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Sep 3, 2013

Hon. Peter MacKay
509s Center Block
House of Commons
Ottawa, Ontario
K1A 0A6

RE: FINA Pre-budget consultations – Recommendations affecting Justice Canada

Mr. MacKay

The National ME/FM Action Network would like to welcome you to your new position as Minister of Justice. We look forward to working with you to address some very important human rights issues related to Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) and Fibromyalgia (FM).

Our organization is a registered Canadian charity working on behalf of Canadians with ME/CFS and FM. According to Statistics Canada's 2010 Canadian Community Health Survey, there were over 750,000 Canadians who had been diagnosed with one or both of these conditions. The survey also shows that these conditions are very disabling. We would like to point you to statistics at on our website that show how disabling ME/CFS and FM are in comparison to other well know medical conditions.

http://mefmaction.com/images/stories/quest_newsletters/Quest80springsummer2009.pdf

Canada has a system for supporting Canadians with disabilities. The system includes accommodation at work or school, income supports for people whose disability impairs their ability to work, and strategies to encourage participation in the community. The disability system has its strengths and weakness that need constant attention. We, like many other disability groups, would encourage the government to review the current system in light of the new United Nations Convention on the Rights of Persons with Disabilities.

Canadians with ME/CFS and FM have challenges above and beyond those encountered by people with classic disabilities because the disabilities that come with ME/CFS and FM are not well known or recognized. Time and again, people with ME/CFS or FM are called upon to prove that they are disabled or to convince authorities that their impairments qualify for disability services. Many programs or services take a narrow view of disability that excludes the ME/FM

community. The disability system is meaningless for people with disabilities who cannot access it. There is enormous suffering in the community because of these human rights issues.

With this in mind, our organization made a submission to the pre-budget consultation process of the House of Commons Finance Committee's (FINA). A copy of our submission is attached. As you will see, one of our recommendations is the establishment of an inter-departmental task force co-chaired by an official of Justice Canada to review government information, services and programs to ensure inclusion of the ME/CFS and FM community. Your Director-General for Human Rights conveyed to us her discomfort with taking a leadership role rather than an advisory role. We believe that this is an area where Justice leadership would be extremely valuable.

We hope to have the opportunity to meet with you and your staff before Parliament reconvenes this autumn to discuss this recommendation and other issues affecting our community.

A handwritten signature in black ink, appearing to read 'M Parlor', with a long, sweeping horizontal stroke extending to the right.

Margaret Parlor
President
National ME/FM Action Network